

Assembly Concurrent Resolution No. 151

RESOLUTION CHAPTER 98

Assembly Concurrent Resolution No. 151—Relative to Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week.

[Filed with Secretary of State July 15, 2014.]

LEGISLATIVE COUNSEL'S DIGEST

ACR 151, Wilk. Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week.

This measure would declare the week of May 25, 2014, to May 31, 2014, inclusive, as Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week to honor those who work to make research and resources a reality for children suffering from DIPG and their families.

WHEREAS, The Legislature recognizes that the quality and character of life in the communities across the State of California are reflective of the concerned and dedicated efforts of those organizations and individuals that are devoted to the welfare of the community and its citizenry; and

WHEREAS, In this regard, the Legislature commends the efforts of the Jack's Angels Foundation and other similar foundations for their continuing efforts to raise awareness of, and fight against, malignant brain tumors; and

WHEREAS, James-William "Jack" Demeter, the namesake of the Jack's Angels Foundation, lost the fight against Diffuse Intrinsic Pontine Glioma (DIPG) at the age of three; and

WHEREAS, DIPG is a malignant brain tumor that affects the brain stem. Only children are afflicted with DIPG and it is usually diagnosed between five and nine years of age; and

WHEREAS, According to Dr. Sabine Mueller of the University of California at San Francisco, DIPG is one of the worst diagnoses a patient and his or her family can face. There are essentially no long-term survivors and median survival is only about 9 months. Progress has been hampered by the perceived risk of biopsy of these tumors. To date, no therapy has been shown to be effective and children with DIPG are often treated on early phase 1 clinical trials with a trial-and-error approach; and

WHEREAS, The Jack's Angels Foundation is a nonprofit corporation that donates all money raised to establish a new DIPG research fund at the Los Angeles Children's Hospital. The foundation is committed to promoting the most innovative research and clinical trials to help shed light on the nature of DIPG and the genetic anomalies that cause it. In order that there be greater hope for survival, the foundation also actively researches cures for DIPG through medical trials and scientific research; and

WHEREAS, The mission of the Jack's Angels Foundation is also to support the quality of life for patients diagnosed with DIPG patients and their families; and

WHEREAS, The mission of the Jack's Angels Foundation also includes increasing public awareness and understanding of DIPG, potentially increasing the protocol for pediatric brain tumor research, and increasing investment by pharmaceutical companies in research pertaining to DIPG; and

WHEREAS, It is the intent of the Legislature to call attention to organizations, like the Jack's Angels Foundation, that serve to bring people together for the united purpose of actively pursuing improvements in their communities; now, therefore, be it

Resolved by the Assembly of the State of California, the Senate thereof concurring, That the Legislature pause in its deliberations to honor those who raise awareness of, and fight against, malignant brain tumors, including DIPG; and be it further

Resolved, That the Legislature hereby declares the week of May 25, 2014, to May 31, 2014, inclusive, as Diffuse Intrinsic Pontine Glioma (DIPG) Awareness Week to honor those who work to make research and resources a reality for children suffering from DIPG and their families; and be it further

Resolved, That the Chief Clerk of the Assembly transmit copies of this resolution to the author for appropriate distribution.